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Experience of Stigma and Discrimination in Families of Persons with Schizophrenia in the Czech Republic

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Declaration of interest

Authors have no conflict of interests to declare.

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Abstract

Rationale: Mental health-related stigma and discrimination not only affect persons living with schizophrenia but also their whole families. Stigma and discrimination reduction is key to respond to the unmet needs of persons with mental illness. The local context is of particular importance in this endeavor, as stigma and its manifestations depend on the specific conditions of the target population and across cultures and settings. Evidence on effective approaches to reduce stigma is sparse and lacking from Central and Eastern Europe, including from the Czech Republic.

Objective: Our aim was to inform a far-reaching anti-stigma campaign related to a national mental health reform that was being deployed.

Methods: We conducted a qualitative study based on semi-structured in-depth interviews with relatives of patients diagnosed with schizophrenia in the Czech Republic. Initial respondents were identified through local mental health services and users' organizations with a consecutive chain-referral sampling. Transcribed narratives were thematically analyzed within a pre-developed four-level thematic framework to comprehensively identify experiences of stigma and discrimination in all areas of the respondents' lives.

Results: Stigma experiences of 25 diverse family members of persons living with schizophrenia spanned four levels of respondents' lives (macro-, meso-, micro-, and intro-level). The overarching issues were: (1) general lack of understanding and misconceptions about mental illness; (2) structural discrimination and paucity of governmental and public support system; (3) burden of "pervasive and unlimited" care and inability of independent living.

Conclusions: We identified several features of mental health related stigma and the ensuing discrimination in Czech Republic experienced by persons with severe mental illness and their relatives. We developed a set of recommendations for policy-makers aimed at reducing ignorance and prejudice amongst the public and professionals, improving health and social services—including employment, housing and community integration—and the provision of family support.

Key words: stigma; schizophrenia; family studies; mental health service; Central and Eastern Europe

Introduction

Worldwide, persons with mental disorders are highly exposed to stigma, discrimination, and social exclusion, which may be more burdensome than the mental illness itself (Link & Phelan, 2001; Thornicroft, 2006). Moreover, ill mental health may also elicit negative attitudes towards family members of persons with mental illnesses (Corrigan & Miller, 2004; Phelan et al., 1998). The process of transferring stigma from people with mental illness to their companions and relatives and discrediting them is described in the literature as "courtesy stigma" (Angermeyer et al., 2003; Goffman, 1969), "associative stigma" (Mehta & Farina, 1988), "stigma by association" (Goldstein & Johnson, 1997; Neuberg et al., 1994; Ostman, 2002) or "family stigma" (Park & Park, 2014; Phelan et al., 1998). Stigma is widespread (Koschorke et al., 2014; Nadia Kadri, Fatiha Manoudi, & Soumia Berrada, 2004; Shibre et al., 2001), exists in different domains of life (Buizza et al., 2007; Gaddis et al., 2018), and associated with both subjective and objective burden on family members (González-Torres et al., 2007; Kjellin & Margareta, 2002; Larson & Corrigan, 2008; Lefley, 1989; Muhlbauer, 2002; Phelan et al., 1998; Shibre et al., 2001; Struening et al., 2001; Zou et al., 2014).

The identification of effective approaches to reduce the stigma of mental illness is among the top priorities of global mental health (viz., "developing culturally informed methods to eliminate the stigma, discrimination and social exclusion of patients and families across cultural settings," Collins et al., 2011). The cultural context of stigma is of crucial importance because the homogeneity of stigma as a concept, as well as the universal application of anti-stigma campaigns, have been questioned (Hanzawa et al., 2010; Stuart et

al., 2012). Stigma depends on and varies across settings and the specific conditions of target populations, as it relates to *"What matters most"* (or what is most "*at stake*") in a particular setting and culture (Yang et al., 2014). Culturally-specific stigma studies are still lacking, and most studies on the subject used Western-developed stigma measures or lacked explicit stigma-specific conceptual frameworks (Yang et al., 2014). Evidence from Central and Eastern Europe on stigma is particularly limited, especially on stigma experienced by family members and carers (Evans-Lacko et al., 2014; Winkler et al., 2017).

Two recent studies focused on family stigma experienced in the region, in particular from Belarus, focusing on the dissolution of families following a diagnosis and salient anticipation of stigma in the secondary social group (Krupchanka et al., 2016); and the structural discrimination within mental health care, during employment, and in contact with the police (Krupchanka et al., 2017). Family image was the main value under the threat of stigma. Further, the presence of mental illness interfered with the possibilities of creating one's own family and with building careers for all family members (Krupchanka et al., 2016).

Evidence of this type from the Czech Republic is useful to inform ongoing national mental health reform (MHCZ, 2013) and planned national anti-stigma campaign. In this study, we had two aims: First, to comprehensively overview stigma-related challenges in different areas of life of family members (FMs) of persons living with schizophrenia (PLS); and second, to formulate 'what matters most' to individuals under the threat of stigma in the Czech context. The ultimate goal of this study was to provide recommendations to decision- and policy-makers on reduction of stigma-related burden in families.

Method

We focused on the broad range of participants' experiences of stigma, defined as examples of "devaluation experienced by family members because of the presence of

schizophrenia within the family." We used a qualitative research methodology to take into account the perspectives of the study participants (Brown, 2001; Hudelson, 1994).

Data Collection

Four native Czech-speaking researchers (DC, MV, MC, TR) collected data between September 2015 and June 2016 in consultation with other researchers (DK, MJ). We contacted local mental health care providers, service users, and family associations to recruit initial participants (family members of persons with severe mental illness). The chain-referral sampling methods were applied to reach more respondents according to pre-specified socio-demographic characteristics. We aimed to have as diverse a sample as possible with representatives of different demographic groups (with different age, sex, degree of relation to the person with mental illness, duration of PLS illness, and rural/urban area of residency). The data collection continued until the theoretical saturation was reached when additional interviews were not providing any new information. Prior to approaching the identified respondent, we contacted the patient to obtain his or her written permission to interview the relative. After that, we invited a selected respondent for a meeting at the place of his/her convenience, asked to sign an informed consent, and conducted a semi-structured in-depth interview (Dicicco-Bloom & Crabtree, 2006) according to a pre-developed topic guide (Appendix A). Interviews lasted one to two hours, were conducted in Czech, recorded digitally, and transcribed verbatim.

Data Analysis

Data were processed by thematic analysis to elicit repeating and salient themes (Braun & Clarke, 2006). In line with the study aims, we used thematic analysis as an

essentialist/realist method with a semantic/explicit level to identify themes. Rather than uncovering broader social meanings of stigma within a constructionist approach, we decided to report the experiences and everyday life of participants, which may help establish concrete recommendations for the national policy reform. Taking into account our previous research on the topic, we decided not to rely on a purely inductive methodology, but rather to use a theoretical (deductive) approach to analyze the data. We used a pre-designed four-level thematic framework, which consists of four levels of experience: (1) macro-level of general society awareness and views; (2) meso-level of formal governmental support and while interacting public agencies; (3) micro-level of life within a local community (neighbors, colleagues, friends); and (4) intro-level of life within a family. The reason for utilizing this framework was to comprehensively capture experiences of stigma in all areas of respondents' lives, so that the findings would be applicable for multi-level anti-stigma interventions.

We analyzed data following the logic of iterative categorization (Neale, 2016) in line with the four-level thematic framework. However, the coding of themes within the four levels was conducted without pre-existing coding frame (i.e., was data-driven). Two bilingual members of the research team (DC, MV) independently coded each interview in the NVivo 11 qualitative software program in close consultation with two other members of the group (DK, MJ). Researchers started by listening and reading interviews to familiarize themselves with the data. They extracted words, phrases and larger sections of text which related to experience or perception of stigma and collated those with similar or related meanings into candidate themes. The themes were further enhanced, reviewed, and restructured in an iterative process accompanied with regular discussions between researchers. After the coding was completed, all emerging themes with related citations were exported to Microsoft Word, translated into English by professional translator, and iteratively categorized and revised

within the bigger group of researchers (DC, MV, DK, DM). The thematic map was further refined until final agreement was reached within the research group. The final thematic map and its description was used to build upon the data interpretation, recommendation, and conclusions.

In addition, to assure correct interpretation of data within the analysis, we performed a respondent validation exercise. Study results and conclusions were presented and discussed within the group of five study participants. Overall positive feedback was achieved from respondents who agreed with the content and conclusions of the study. Additional comments were given with regards to the necessity of wide dissemination of the study.

The study was approved by the Ethical Committee of the National Institute of Mental Health (approval No. 53/15 dated 15 April 2015).

Results

Participants

Socio-demographic characteristics of the sample are presented in Table 1. The sample consisted of 25 relatives of persons living with schizophrenia (PLS), with a median age of 53 years; 13 were married (53%); 10 lived in a major/urban city (Prague; 40%); and 18 were female (72%). The sample included a diverse range of relatives of PLS among which mothers were the majority (44%), followed by siblings (28%), fathers (12%), partners (8%), or distant relatives (8%). The majority (68%) of respondents were relatives of PLS with a long (10-20 years) or median (5-10 years, 16%) history of mental illness. The final thematic map and supporting citations appear in Table 2 and in the supplementary online materials.

<INSERT TABLES 1 AND 2 ABOUT HERE>

Experience of Stigma at the Macro-Level of General Society Awareness and Views

At the macro-level, respondents described their experience with the general public and their impression of the mental health awareness in the country. In particular, they mentioned (1.1) incorrect coverage by the media and (1.2) insufficient public education in the field of mental health, resulting in a very low awareness, lack of information, and misconceptions in society about mental disorders.

1.1) FMs felt that the negative picture of PLS and of the schizophrenia diagnosis in the population is substantially fueled by incorrect messages and lack of objectiveness in the media.

"…media just serve us in a negative way and say, if there is somebody under ...that...treatment or in the hospital for mentally ill people then they consider them an insane person right away, a maniac and deviant and so on, so ...it has certainly some influence and I also went through that when I experienced that." (M9pokus_B)

"I feel anxious now when I am talking about that because they started avoiding me because they were afraid, mainly due to how media present mentally ill people, and how they emphasize what a mentally ill person did." (M1)

1.2) FMs reported lack of knowledge and misconceptions held by the public.

"…the society has no idea what to imagine under this term (schizophrenia), and if you tell them, they imagine a person who starts killing in a minute or will commit something really terrible." (D_10)

Experience of Stigma at the Meso-Level of Governmental Support and While Contacting Public Agencies

At the level of formal governmental support and while contacting public agencies, respondents reported experience of discrimination that was grouped within (2.1) medical and (2.2) undignified environments and bad conditions, (2.3) non-medical support, (2.4) job-opportunities for PLS, (2.5) contact with police, and (2.6) legal consequences of diagnosis disclosure.

2.1) In the system of **medical support** there were a number of issues perceived by respondents as inappropriate and devaluating, both in (a) in-patient and (b) out-patient levels of care.

2.2) Interviewees described **undignified environments and bad conditions** in psychiatric hospitals. In particular, they described crowded rooms (up to ten people in the ward), thefts, insufficient hygiene, lack of staff, and insufficient communication between staff.

Additional attention was given to in-patient treatment of patients. Over-medication was reported as a common practice leading to the condition of "deadened" or "sleeping" patients, who were furthermore not allowed to spend time in their bedrooms because of the practice to lock rooms during the day.

"Now I saw there, how those guys lie around, sleep on the carpet or on three chairs pushed together, such old fatty guys, I got scared so much. And I said, my God, I went into shock when I saw them sleeping on tables and said, why are not they in bed, for God's sake, what is this? They lie around on the floor and tables..." (D8)

Insufficiency of hospital treatments that help patients reach a stable state and particular difficulties in assuring continuation of care were mentioned as problematic. Respondents felt

that the time immediately after the discharge from hospital was particularly stressful because they received almost no support from the service, which left the care of the patients entirely in the hands of the families.

"…someone is discharged from the psychiatric hospital and what...what...what to do about him or her, then?" (M5_U)

Access to the out-patient and community care was geographically limited in remote areas, which forced people to travel for long distances to reach the facilities. Special difficulty was expressed by respondents with regards to very limited time spent by professionals with patients or formality from the personnel. Increasing provision of psychotherapeutic care and better capacity of sheltered/social housing were also perceived as additional areas requiring attention.

"…it is 100 kilometers, like 50 there and 50 back, the whole day is wasted." (D7)

"You come, he prescribes medication for you, has fifteen minutes to spend with you and nothing more and ... he sometimes did not want to see me…" (D5,6)

"… the field worker asks only "do you take medication? Have you washed? Do you eat something?"...to check off the items in papers, simply, it does not help that person." (D_10)

2.3) In the system of **non-medical support**, there was a salient problem of insufficient assistance available to families and patients. In particular, disability pensions awarded to PLS were mentioned as far too low for independent living, which forced families either to provide constant support of PLS or let them live in poverty. Furthermore, the procedure of granting a pension and social benefits was described as unacceptably long, burdensome, and offensive, one that PLS were mostly not able to endure alone.

"But those questionnaires. Do not be angry but when I saw them...I feel offended on behalf of brother who completed it without thinking. But I was about to start crying. Why is he supposed to complete it, if he isn't able to wipe his bottom? Where are we? Like this...this...are we serious about that, that based on this I will determine then, what kind of money that person deserves?" (M_2)

2.4) Respondents also mentioned **lack of assistance with employment** for PLS, such as insufficient number of employment assistance programs, short duration of available programs, and lack of staff competent to support PLS and their families at the employment offices.

"There exist many associations and sheltered workshops here but it is not enough and not all of them are adapted to work with people with mental disorders." (D10)

Employment of PLS was presented as a substantial difficulty because of limited job opportunities. There were examples when the mark of psychiatric treatment led to dismissals and access only to low-paying jobs for PLS.

"…it was obvious that he is a psychiatric patient because there was a stamp. Then they dismissed him so he was changing the job, they did not pay him his wage, he was at the employment office for a long time." (JJ_M8)

2.5) Experience of **contact with the police** was in some cases difficult, mainly because the police staff were not skilled to deal with sensitive issues surrounding mental illness ("sort of heavy-handed" (M2)) and were not able to recognize symptoms of mental illnesses.

"He experienced that the police took him away instead of calling the ambulance...it is hard to talk about that and I always feel like crying; they took him to the interview room and stripped him and beat him, kicking him and ... because they did not know he is ill, they simply thought that he is under the influence of drugs and alcohol." (M1)

2.6) Families also expressed a fear of possible **legal and institutional consequences**, or sanctions that might be imposed by governmental institutions because of diagnosis presence in the family. They worried about unfavorable court decisions, getting children taken out of parental custody, unreasonable sentences for PLS, being evicted, and that social services would come for inspections.

"These are so called, how I can say it...my personal mania or fears that they will sentence us, order eviction, invite social services, that we might be dangerous because we have such diagnosis." (M_1)

Experience of Stigma at the Micro-Level of Life Within a Local Community

At the level of community, respondents were worried about (3.1) **the attitude of people** towards those with mental illnesses and the whole family and reported (3.2) avoidance of disclosure of the mental illness, as a result of anticipated stigma. Particular examples were given in relation to the lack of understanding and distancing of people within local communities.

3.1) **Attitude of the community** was characterized in two main streams, one being fear and suspicions towards the PLS, and the other being aggressive behavior and negative sentiments framing the PLS as a "parasite" due to their lack of productivity and contribution to society.

"So since then, because he got this diagnosis and as you say, people are scared of it, nobody wants to communicate with him." (D_13)

"… Some of them condemn us ... or they say, for example, put her somewhere in the institution, she bothers us." (pí_Ř_M6)

3.2) **Avoidance of disclosure**: To avoid this type of reaction and discrimination in the community, family members often kept the illness a secret. They were reluctant to speak about mental health issues with their friends, colleagues, and neighbors and in general had difficulties in making friendships or opening up to people within the surrounding. Respondents were worried and afraid of potential consequences of the diagnosis disclosure, such as gossip, unnecessary additional attention ("sensation"), and condemnation.

"Well, I rather think that it looks like I do not like talking about that, so ... rather the reluctance to talk about that with them because some people are just, they talk nineteen to the dozen and I do not like it." (D_14)

"Because of the stigmatization, I think, it is very hard to make friends or to open one´s heart to the people from neighborhood with that we experience." (M_1)

Experience of Stigma at the Intro-Level of Life Within a Family.

At the level of intra-family life, a substantial burden of care was described by respondents as (4.1) the **need to provide "unlimited care" to the PLS**. In addition, we recognized (4.2) **endorsement of stereotypes within the family**.

4.1) With regard to **"unlimited care,"** families experienced (a) financial dependence of PLS on family members, (b) devotion of personal time to taking care of PLS, (c) ongoing responsibility for life of PLS, and (d) suffering from an emotional burden.

a) Lack of financial support and problems getting a well-paid job by PLS have already been mentioned previously at the meso-level of respondents' experience as presenting severe barriers for PLS to live independently. This situation, in turn, forces families to cohabitate with PLS, to support the PLS financially, and/or to incur additional costs.

"The financial situation is not good, I would say that without the help of relatives we could not live in ...in a common household or independently…We know that many of our friends with mental disorders still live with their parents, they do not have enough money to become independent…" (M1)

b) For those providing direct care, an important issue was the need to spend much of their personal time with the PLS, which took up time from their personal lives and shrank space for privacy.

"Our free time minimized, and everything, all time is managed according to son. It means that it is like some sort of loss of privacy in any case." (D_10)

c) In addition, family felt they had to serve as a "protective shield" and take responsibilities for a majority of the administrative issues and life problems of PLS.

"So the life is for him very difficult in the society...very difficult. To the certain extent we are able to eliminate it because we arrange many things related to the agencies, we arrange everything with him for hundred percent." (D_10)

d) One of the most significant elements of the overall burden associated with stigma and discrimination was an emotional one. It started at the very beginning of the illness with the shock, unpreparedness, and lack of understanding and knowledge of what was going on and where to get help. It also included all-pervading feelings of guilt,

self-blame, and continuous attempts to explain the origin of the illness as a personal mistake.

"It was a terrible shock…the worst thing is that you are not ready for it and you do not know that something like can happen…If it happens, you are absolutely taken by surprise and arehopeless." (M5_U)

"…at the beginning, I could not bear it because I was asking myself what I did wrong, what caused it, could I stop it or could not I stop it, where is the mistake…" (D_9)

Hopelessness and helplessness, worries about an unclear future ("I will not be here forever"), and regrets about lost opportunities of "normal life" were also mentioned.

"I am just worried most about...about my age and if I left, he would stay on his own. Just...I could not sleep many times thinking." (D_1,2)

4.2) Even within a family there were examples of **prejudice toward PLS**, such as a perception of schizophrenia as contagious. Similar to the prejudices expressed on the micro-level of life within the local community, some family members (a) presented fear of dangerousness of PLS, (b) believed in unreliability and incapability of PLS, or (c) distanced themselves from the PLS.

"…he (first-born son) decided that schizophrenia is an infectious disease. So, he is careful and does not keep in touch with X at all as well as with me because I am in touch with X." (D_1,2)

"I would be worried myself to give him the children, I was scared…" (D_12)

"Well, because I would not employ a problematic person, to have problems, when I can employ a normal person instead." (D_12)

Discussion

The study presents an overview of stigma-related challenges in different areas of life experienced by family members of persons with schizophrenia in the Czech Republic. We found that stigma and discrimination were present at all levels of respondents' lives (macro-, meso-, micro-, intro-), suggesting its pervasive nature. These issues can be summarized within three main topics: (1) general lack of understanding and misconceptions about mental illness; (2) structural discrimination and paucity of governmental and public support systems; (3) burden of "pervasive and unlimited" care and inability of independent living.

The experienced lack of understanding and misconceptions about mental illness was apparent on all thematic levels. At the societal level, participants reported public stigmatizing attitudes and incorrect messages in the media, which is in line with the evidence found in printed media analyses in the Czech Republic (Nawka et al., 2012; Nawková et al., 2012). At the local community level, respondents mentioned lack of understanding and fear of PLs and resulting condemnation and aggressive behavior, which lead to FMs avoiding disclosure of diagnosis. As another recent study documented, 30.8% of the Czech general population are unwilling to have a person with mental illness as a neighbor and 26.4% are unwilling to have one as a friend (Winkler et al., 2015). Evidence of ignorance, misconceptions and endorsement of prejudices was also apparent at the family level, such as beliefs about "infectiousness" of schizophrenia, which reflects a particular example of family beliefs about contagiousness of mental illness (Larson & Corrigan, 2008).

Structural discrimination and insufficiency of support systems was reflected in poor medical care, including inappropriate and undignified conditions within medical services. Psychiatric care was characterized by over-medication of patients and a rigid system with lack of attention to individual needs, insufficiency of follow-up after hospital discharge, and

difficulty to access out-patient and community care. Underdevelopment of community care and its insufficient regional coverage, as well as stigmatizing attitudes of Czech medical doctors (Winkler et al., 2016) are persistent problems in Czech mental health care (Hoschl et al., 2012). The intensity of structural discrimination and the institutionalized nature of care may play a role in generating more public stigma and in reinforcing existing stereotypes towards PLS and their families. This institutionalized nature of care is a potential explanation of the substantially higher prevalence of stigmatizing behavior toward people with mental disorders in Czech general population when compared to England, for example (Winkler et al., 2015).

The overall burden of "pervasive and unlimited" care was the overarching and salient issue throughout all levels. The exposure to public misconception, lack of formal and informal support, financial and emotional difficulties, and isolation were additionally amplified by the FMs' inability of having independent personal life due to their full involvement in the PLS's caregiving.

Recent stigma research has suggested that to understand the experience of stigma it is necessary to understand what is "at stake" under the exposure to stigma and discrimination in a specific cultural context. In other words, what is threatened by stigma is a person's ability to participate actively and achieve "what matters most" in society to reach "full status" or "personhood" (Yang et al., 2014). Different manifestations of "what matters most" have been identified, ranging from "loss of face" and family credibility in China (Yang et al., 2007); being able to meet gender-specific social role expectations in India (Koschorke et al., 2014); taking responsibility for others, such as parenting and contributing to the well-being of kin

and the community in Ghana (Read et al., 2009); and, loss of family image, damaging an individual's chances to extend their family or be successful in career in Belarus (Krupchanka et al., 2016). Whilst nuances and intensity of stigma vary across cultures, there are emerging trends in international cross-cultural studies showing that stigma affects similar domains of individual's lives, such as employment and marriage (Knifton, 2012).

In individualistic Western societies, "what matters most" was found to focus on being able to exhibit productivity or competitiveness necessary for obtaining high-performing jobs (Schulze & Angermeyer, 2003). Similarly, in this study the overarching theme of the desire to "live independently as a productive member of society," expressed as an issue across all domains by FMs, highlights that in the Czech Republic, too, this value reflects "what matters most" and what is "at stake" as a result of stigma and discrimination. Somewhat counterintuitively, the issue of marriage and stigma as a threat to marital prospects was not mentioned by respondents of the current study, which might be explained by a value change in Czech society that occurred after the fall of communism. This issue could be explained as a consequence of the values shift happening in the Czech society that followed the international trend of deinstitutionalization and decreased value associated with marriage (Treas et al., 2014). This assumption may be indirectly supported by some national statistics, such as the decline in marriage rate during last 25 years (Hašková & Rabušic, n.d.; Rabušic, 2001) and the concomitant increase of extra-marital births (Panasenko, 2013; Štípková, 2015).

Policy Implications

The findings from this study gave us an insight into the experience of stigma in the Czech Republic and allowed us to produce a set of recommendations; these recommendations will help set the mental health reform's priorities in order to enable PLS to lead independent

and fulfilling lives. We found that the different issues and levels are closely connected and that improvements on one level could substantially alleviate the issues at other levels. The overarching cause for stigma appears to be lack of awareness and education. In public agencies this is connected to inappropriate medical care and difficulties accessing pensions and employment opportunities. On community and family levels, lack of education is linked to isolation and burdens carried by caretakers and PLS. We hypothesize that education on all levels is the most pressing issue and may be necessary as the first step in tackling stigma in the Czech Republic.

These findings are useful because they can inform the Czech national program on the reduction of stigma-related burden on families of persons with schizophrenia. Interventions should target the general population, professionals involved in the provision of care, and communities and families (Beldie et al., 2012; Koschorke et al., 2017), and should aim to improve knowledge, address misconceptions, halt structural discrimination within and outside medical services, and increase support for family members. These recommendations should be used to inform the ongoing mental health care reform occurring in the Czech Republic (MHCZ, 2013).

Limitations

Some limitations are worth noting. First, participants were recruited through local mental health care providers and users' associations. The views of people who have less access to services were not captured, and their experience of stigma may differ from regular service users. It is also possible that we interviewed family members who are more cooperative and stay in positive contact with PLS rather than underrepresented views of those

who broke off contact with PLS patients. Indeed, the study sample predominantly consisted of female family members who were more accessible and involved in caregiving, more interested in participation, and more cooperative in providing information. Though we included male respondents in the study, it is possible that their stigma experiences were underrepresented in our study. Alternatively, it is also possible that men are less affected by associative stigma. Further research is needed to clarify this assumption. Second, we used a theoretical (deductive) approach to analyze the data to comprehensively capture experiences of stigma in all areas of respondents' lives. This approach may have constrained the depiction of some experiences of stigma and their allocation to anticipated categories. For example, comments about caregiver burden were often linked to the lack of wider societal structures and systems, or to perceived stigmatization from the community. However, the respondent validation exercise and the revision and refinement of the analysis did confirm the robustness of our approach and the trustworthiness of the themes that emerged in our findings. Third, we cannot exclude possibility that the range, severity and salience of stigma experienced by family members may have been underestimated due to social desirability bias.

Conclusions

We identified several features of mental health related stigma and the ensuing discrimination in Czech Republic experienced by persons with severe mental illness and their relatives. We developed a set of recommendations for policy-makers aimed at reducing ignorance and prejudice amongst the public and professionals, improving health and social services—including employment, housing and community integration—and the provision of family support. Our main findings, the limitations of our study, and its qualitative rather than quantitative approach prompt the design and conduction of more research on stigma in the

Czech Republic and the whole region of Central and Eastern Europe. A clear understanding of the phenomenon is indispensable to adjust and make anti-stigma efforts more effective.

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Table 1
Socio-demographic characteristics of the sample.

Variable	*N (%)*
Gender	
Male	7 (28%)
Female	18 (72%)
Age (Median of age (*IQR*))	53 (42, 63)
Marital status	
Single	5 (20%)
Married	13 (52%)
Divorced	6 (24%)
Widow/Widower	1 (4%)
Location	
Prague	10 (40%)
Big City	6 (24%)
Small City	6 (24%)
Village	2 (8%)
Unassigned	1 (4%)
Family relationship:	
Mother	11 (44%)
Father	3 (12%)
Spouse /Partner	2 (8%)
Siblings	7 (28%)
Other (Distant relatives)	2 (8%)
Length of patient's disorder:	
Less than 1 year	1 (4%)
1-5 years	2 (8%)
5-10 years	4 (16%)
10-20 years	17 (68%)
Unassigned	1 (4%)

Table 2

Final Thematic Framework.

Macro-level of general society awareness and views
1.1. Incorrect coverage by the media
1.2 Lack of awareness, lack of information in public in general
Meso-level of formal governmental support and while contacting public agencies
2.1. Inappropriate medical support for PLS and their families
a. Inpatient care: discriminatory practices and conditions in mental hospitals
- Undignified environment (crowded rooms, insufficient hygiene, locked rooms, thefts)
- Over-medicalization ("deadened," sleeping patients)
- Lack of staff, insufficient communication between staff and relatives
- Insufficient treatment at hospital, difficulties with follow-up care
b. Out-patient and community care: poor access, lack of time, lack of psychotherapy, formality of doctors
- Poor accessibility of outpatient care in regions
- Insufficient capacity of sheltered / social housing
- Little time for a patient
- Attitude/formality of personnel toward PLS
- Poorly available and provided psychotherapeutic care
2.2. Insufficient non-medical support for families and PLS
a. Insufficient financial support ("pension is not sufficient for independent living")
b. Complicated procedures of granting a disabled pension and social benefits (long, burdensome paper amount, requires assistance by relatives, offensive)
d. Insufficient non-financial support for families from the state (access to information, training)
2.3. Limited job opportunities for PLS
a. Difficulty to keep/find a well-paid job for PLS (dismissal, low-paid job)
b. Lack of professional adaptation, rehab, support at working place (insufficient number and duration of sheltered workshops for PLS; lack of qualified people and support at employment offices)
2.4 Policemen do not know how to approach PLS nor always recognize symptoms of mental disorder
2.5 Fear of institutional (legal) consequences/sanctions of diagnosis disclosure
Micro-level of life within a local community (neighbors, colleagues, friends)
3.1 People in the community scared and distanced, lacking understanding
3.2 Fear of social consequences of diagnosis disclosure, concealment
Intro-level of life within a family
4.1 Family burden of "unlimited care"
a. Necessity to provide constant financial support (impossibility of independent living, illness affects the income of the family, family needs to provides support)
b. Necessity to devote much time to take care of PLS (sacrificing life, lack of privacy)
c. Necessity to take much of responsibility for life of PLS (need of protection ("protective shield"), dealing with majority of administrative issues, solving problems**)**
d. Burden of emotions
-Shock/dispair, lack of understanding and knowledge in the beginning
-Self-blaming, guilt ("what was the mistake?")
-Hopelessness, helplessness
-Worries about the future ("I will not be here forever")
-Regrets (remorse, pity?) about the fact of mentally illness

4.2 Sharing/agreeing with stereotypes within a family

a. Fear of the ill relative in the family

b. Believe in the incapability (distrust in the abilities of the PLS)

Research Highlights

- There is general lack of public understanding of mental illness.
- Stigma spans across all levels of life in families of persons with schizophrenia.
- Structural discrimination and lack of governmental and public support endure.
- Caregivers experience a burden of “pervasive and unlimited” care.
- Active participation of person in social life is the main issue at stake of stigma.